The Office On Health and Disability: Strategic Plan 2002

Massachusetts Department of Public Health
Bureau of Family and Community Health
Division for Special Health Needs

Executive Summary

The mission of the Office on Health and Disability (OHD) of the Massachusetts Department of Public Health (MDPH) is to promote the health and well being of people with disabilities and chronic conditions in Massachusetts.

Since 1997, the OHD has been a focal point in state government for leadership in addressing the public health needs and concerns of people with disabilities in Massachusetts. The health of people with disabilities ranks high on the public health agenda in Massachusetts.

Yet people with disabilities in Massachusetts still have many urgent health needs. People with disabilities are more likely to be at risk of smoking, obesity, and poor health outcomes such as depression, diabetes and heart disease than people without disabilities. Women with disabilities are more likely to have experienced intimate partner abuse and sexual assault, and older women with mobility disabilities are less likely to have had mammograms[1].

Addressing these needs requires inclusion, research and surveillance, quality health care, and empowerment. The core goals of OHD address these issues.

Core Goals of the Office on Health and Disability

1. **Assure access and inclusion of people with disabilities in all health promotion activities; create targeted programs as needed.**

2. **Ensure availability and use of data to:**
   - **determine prevalence of disabilities;**
   - **identify health and related needs of individuals with disabilities;**
   - **plan and evaluate services.**

3. **Improve access to and quality of health care for people with disabilities.**

4. **Build and expand a health and disability constituency that fosters individual and organizational awareness and collaboration to promote health and well being.**

These goals were developed by the staff of OHD and the OHD Advisory Council.

At this point in the development of health promotion for people with disabilities in Massachusetts, OHD is ready not only to promote health for people with disabilities in our own state, but also to assist other states interested in pursuing these goals.

These goals are grounded in a view of disability and health promotion that focuses on the interaction of the individual and the environment, as exemplified by the definitions used by the World Health Organization and the Centers for Disease Control in Healthy People 2010:

> **Health**: Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (World Health Organization).
>
> **Disability**: The general term used to represent the interactions between individuals with a health condition and barriers in their environment (Healthy People 2010).
>
> **Health promotion**: Efforts to create healthy lifestyles and a healthy environment to prevent medical and other secondary conditions, such as teaching people how to address their health care needs and increasing opportunities to participate in usual life activities (Healthy People 2010).

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Introduction

History of OHD

Over the past ten years, the public health approach to disability has shifted dramatically.

Starting in the 1930's, when MDPH received federal funds to address the needs of "crippled" children as part of its program of maternal and child health since the 1930's, disability implied the failure of public health, and public health responded by ensuring medical treatment for children.

Public health perceptions of children with disabilities began to shift in the 1970's as the movement for inclusion of children with special health care needs in public education gained force.

In 1989 the public health mission expanded to include adults with disabilities. The Centers for Disease Control funded disability prevention in nine states, among them Massachusetts. The new Office of Disability Prevention was housed in the Bureau of Family and Community Health. Over the next eight years, Massachusetts was a leader among the states in shifting the public health approach from an exclusive focus on preventing disabilities toward a recognition that people who have disabilities also require health promotion. This new approach in public health is reflected in the Healthy People 2010 goal for people with disabilities:

> *Promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the U.S. population.* (Healthy People 2010)

In 1997, the Office of Disability Prevention began to focus exclusively on health promotion for people with disabilities. The program's name was changed to the Office on Health and Disability to reflect this new mission, and it was housed in the Division for Special Health Needs, formerly the Division for Children with Special Health Needs. The name of this division had been changed in recognition of the importance of a life-span approach to disability.

Development of the plan

This plan is an update of the OHD strategic plan prepared in 1997. The strategic planning process that produced the plan began when the mission of OHD shifted from prevention of disability to health promotion for people with disabilities. In the first phase of this process, interviews were conducted with expert informants and focus groups were conducted with people with disabilities. These activities elucidated the views on health, health concerns, unmet needs, and barriers to health of the participants. Recently, quantitative research described below has provided us with rich data on health disparities, health risks and health outcomes for people with disabilities. The development of this

plan has been informed by the results of this qualitative and quantitative research, OHD's twelve years of experience in promoting health for people with disabilities, and the input of the providers, public health professionals, voluntary health organizations, state agencies and disability advocates who participate in our Advisory Council. Our plan is also informed by the Healthy People 2010 goals and objectives for people with disabilities. As mentioned above, our mission statement parallels the goal of promoting health for people with disabilities. Furthermore, the first, second, and third goals of our plan promote the Healthy People objectives of improved surveillance and access to health care and health promotion activities.

Plan

Needs assessment

The Massachusetts Department of Public Health has conducted and collaborated on a number of research projects which illuminate the health needs of people with disabilities. The Behavioral Risk Factor Surveillance System (BRFSS), the Massachusetts Survey of Secondary Conditions, the Multiple Sclerosis Survey and the Barriers to Health Care Survey reveal the health issues, barriers to health care, and environmental obstacles that affect people with disabilities disproportionately.

Behavioral Risk Factor Surveillance System (BRFSS)

The BRFSS is a continuous, random-digit-dial (RDD) telephone survey of non-institutionalized adults age 18 and older and living in households with telephones. The BRFSS is conducted in all states as a joint collaboration between the Centers for Disease Control and Prevention (CDC) and state departments of health. The BRFSS collects data on a variety of health issues, including issues related to disability and quality of life

In 1998-2000, the Massachusetts BRFSS included screening questions to identify adults with disabilities. These questions were:

- "Are you limited in any way in any activities because of any impairment or health problem?"
- "Because of any impairment or health problem, do you have any trouble learning, remembering, or concentrating?"
- "If you use special equipment or help from others to get around, what type to you use?"
- "Would you describe yourself as having a disability of any kind? A disability can be physical, mental, emotional, or communication-related."

Adults who answered "yes" to any of the screening questions were asked about the nature of their major impairment, health problem, or disability; how long their activities had been limited; and whether they needed the help of other persons in handling routine needs or personal care.

Persons who responded "yes" to at least one of the screening questions, and whose activities had been limited for at least one year, were considered for this report as having disabilities. Persons with disabilities were classified into two groups: those who needed assistance in handling routine needs or personal care and those who did not need assistance.

The following are highlights from the 1998-2000 BRFSS survey.

Prevalence

Based on data from 1998-2000, 18% of the non-institutionalized Massachusetts adult population reported having a limitation or disability. The most common disabling condition was orthopedic problems (29%) followed by chronic conditions (18%), arthritis (12%), affective problems (8%), and sensory problems (7%). As expected, disability was more common among older adults.

Health Risk Behaviors

An estimated 25% of adults with disabilities smoked compared to 19% of adults without disabilities. The percent of adults who smoked decreased with age for both groups. Overall, adults with disabilities were slightly less likely to be binge drinkers (13%) than adults without disabilities (19%). There was no difference in heavy drinking between adults with disabilities and adults without disabilities.

Obesity was more common among adults with disabilities when compared to adults without disabilities. Adults with disabilities were also less likely to report leisure-time physical activity in the past month, as compared to adults without disabilities.

Health Care Access and Utilization

Five percent of adults with and without disabilities were currently without health insurance. Having no insurance decreased with increasing age for both groups. However, individuals with disabilities were more likely to be underinsured compared with individuals without disabilities.

Individuals with disabilities were slightly more likely to have seen a doctor for a routine check up in the previous year (86%) when compared to individuals without disabilities (77%). Similarly, adults with disabilities were more likely to have had a flu shot in the past year and to have ever received a pneumococcal vaccination as compared to adults without disabilities.

Individuals with disabilities were less likely to have seen a dentist in the past year and to have six or more teeth missing due to disease, as compared to individuals without disabilities.

There was no difference between adults with and without disabilities regarding breast, cervical, and prostate cancer screening. However, older women with mobility impairments were less likely to receive mammograms (52%) than women who did not report a mobility impairment (69%) or women without disabilities (69%). Individuals with disabilities were more likely to have ever had a proctoscopic exam (51%) compared to individuals without disabilities (42%).

While 27% of adults with disabilities were tested for HIV in the past year, only 20% of adults without disabilities were tested.

Quality of Life

One in every four (25%) adults with disabilities reported that pain limited activities for more than half of the previous month as compared to 2% of adults without

disabilities. Adults with disabilities were also more likely to report being sad, blue, or depressed, to have more days of insufficient sleep, and to feel worried, tense, or anxious 15 or more days in the previous month as compared to adults without disabilities. Additionally, adults with disabilities were less likely to be satisfied with their life and feel healthy and full of energy as compared to adults without disabilities.

Among women aged 18-59, those with disabilities were twice as likely to have experienced intimate partner abuse in the past year (10%), as compared to women without disabilities (5%). Intimate partner abuse decreased with increasing age for both groups of women. Women with disabilities were also much more likely to ever have experienced sexual assault (34%) compared to women without disabilities (18%).

Health Status

One in every three adults with disabilities described his or her health as fair or poor as compared to five percent of adults without disabilities. Both physical and mental health were strongly associated with disability status. A similar association was found between disability status and health interfering with usual activities. Adults with disabilities had fewer healthy days in the previous month as compared to adults without disabilities.

Persons with disabilities were more likely to have diabetes, heart disease, high blood pressure, and high cholesterol than non-disabled persons. Moreover, among women age 45 and older, osteoporosis was more common among women with disabilities, as compared to women without disabilities.

Massachusetts Survey of Secondary Conditions (MSSC)

The MSSC surveyed independently living adults with major disabilities in Massachusetts in order to track the impact of environmental factors and risk behaviors amenable to public health intervention (e.g., access to health care facilities, tobacco smoking, personal assistance) on the development of secondary conditions (e.g. urinary tract infections, pressure sores, depression).

Methods

Data gathering occurred in three phases. Participants were recruited from six independent living centers and two health maintenance organizations in Massachusetts. Although the samples were not population-based or random, the organizations were asked to select respondents systematically (e.g., every third name from the alphabetical membership lists). All participants were at least 18 years of age and provided informed consent. No proxy interviews were conducted.

Participants

Demographics

The 656 respondents who participated in the baseline survey were, on average, 44 years old with 13 years of formal education. Fifty-eight percent were women. Almost

73% were white non-Hispanic, 18% were black non-Hispanic, 5% were Hispanic, and fewer than 5% were Native American, Asian, or other racial groups. Half the respondents reported living alone. All but three reported at least one source of health insurance.

Disabling conditions

The most prevalent condition was spinal cord injury (18%), followed by cardiovascular/pulmonary conditions (16%) and cerebral palsy and spina bifida (14%). Psychological, cognitive, and behavioral conditions and arthritis each accounted for 13% of the sample. Almost 21% of respondents had been disabled all their lives; most of them (65% of those with lifelong disabilities) reported having cerebral palsy or spina bifida as their primary disabling condition. Over half (52%) had more than one disabling condition.

Personal assistance needs

On average, respondents required assistance in 3.2 (± 3.1) ADL domains and reported problems with 1.3 (± 1.1) IADL domains. While 68% reported needing personal assistance services (PAS), only 56% received them. Respondents who received PAS obtained a mean of 3.7 (± 4.5) hours/day. More than half the respondents also received some level of unpaid personal assistance.

Secondary conditions

On average, respondents reported 5.3 (± 3.1, range 0-15) secondary conditions, with almost 95% reporting at least one. The five most common secondary conditions were: fatigue, depression, spasm, chronic pain, and anxiety. Fair/poor health outcomes were associated with a greater number of reported secondary conditions.

Controlling for type of disability, functional limitations, and demographics, people with an unmet need for mobility aids, people who used tobacco within the past four weeks, used marijuana in the past 12 months, had difficulty maintaining weight, experienced difficulty with physical exercise, or reported an experience of assault within the past 12 months, were more likely to report a greater number of secondary conditions (Wilber, et al 2001).

Depression

Of the 656 respondents in the baseline survey, 50.2% reported being depressed within the past 12 months. Of those reporting depression, 39% reported being very depressed as compared to 32.5% reporting moderate depression and 28.5% being not very depressed. Almost 65% of those reporting depression were unable to work or go to school, 68% went to see a doctor, 11% to the emergency room, and 14% were hospitalized due to their depression (Mitra et al 2001).

Multiple Sclerosis Survey

In 2001, the Multiple Sclerosis Program surveyed people in Massachusetts with multiple sclerosis. The Massachusetts Multiple Sclerosis Survey (MMS Survey) was a product of close collaboration between MDPH and the Central New England Chapter of the National Multiple Sclerosis Society. The MMS Survey was administered by the Center for Survey Research at University of Massachusetts at Boston which conducted telephone interviews with 319 people. The major objective of the MMS Survey was to gather information on the needs of people with multiple sclerosis and on the barriers they face to health and quality of life.

Examples of barriers included: difficulty getting places, cost of services, difficulty figuring out what type of health specialist to see, and lack of insurance or difficulty paying out-of-pocket expenses for things related to multiple sclerosis. For 70% of respondents, one or more of these barriers interfered with one or more of the following:

- Seeing medical specialists
- Accessing mental health treatment
- Obtaining immunoregulatory drugs
- Making needed home modifications
- Getting needed in-home-help

Preliminary analysis of the data indicates that these barriers were particularly relevant for certain segments of the population with multiple sclerosis. Groups most seriously affected were:

- People with household income of less than $30,000;
- People who had received help in their home in the previous twelve months;
- People who had received personal care assistance in the previous twelve months;
- People who reported poor health status;
- People who reported they saw or should have seen a mental health professional;
- People with mobility problems;
- People not working because of health problems; or
- People living in the southeastern section of Massachusetts

Future directions

Assure access and inclusion of people with disabilities in all public health activities; and create targeted programs as needed.

In pursuing this goal, OHD is fulfilling Healthy People 2010 Objective 6-10, "Increase the proportion of health and wellness and treatment programs and facilities that provide full access for people with disabilities".

Improving accessibility and inclusiveness of programs directed by DPH staff

Build internal awareness through

- Trainings using the *Health Access Curriculum* developed by the North Carolina Office on Disability and Health and OHD; and
- Representing a disability perspective at MDPH events and on committees that include participants from a variety of MDPH divisions and bureaus.

Increase accessibility and inclusiveness of programs by:

- Developing a protocol for accessibility and inclusiveness of all materials produced by DPH, including radio, TV, print, and internet;
- Providing technical assistance to DPH staff to ensure materials are accessible;
- Providing technical assistance to DPH staff to increase program accessibility, particularly in programs with an interest in inclusion of people with disabilities, and where there is evidence that the program could fill unmet needs for people with disabilities (e.g., breast cancer screening, violence prevention, and services for survivors of violence).
- Ensure that health promotion materials are distributed through outlets that will reach people with disabilities, such as agencies that serve people with disabilities.
- Prioritize those materials that address issues such as obesity and smoking for which people with disabilities are at greater risk according to BRFSS findings.

Improve accessibility and inclusiveness of providers contracted with or licensed by MDPH

Strengthen and expand the Americans with Disabilities Act (ADA) Project.

This program requires all providers that contract with MDPH to comply with the ADA. The program is moving from a focus on education and technical assistance to requiring full compliance.

Expand the ADA Project to cover programs licensed by MDPH as well as programs contracted with MDPH.

- Train licensing inspectors to assess ADA compliance.

Assist other states seeking to ensure the accessibility of contracted programs

- Document the ADA compliance program to enable other states to replicate the program with technical assistance from Massachusetts.

Create and implement targeted programs as needed

- Collaborate with voluntary health organizations such as the Arthritis Foundation or the Multiple Sclerosis Foundation on health pro motion targeted at groups with common diagnoses or functional limitations.
- Create interventions targeted at specific health issues for people with disabilities, such as nutrition for people with disabilities.

Ensure availability and use of data to determine prevalence of disabilities, identify health and related needs of individuals with disabilities, and plan and evaluate services.

Conduct outcome and process evaluations of interventions.

Continue BRFSS disability module and asthma module.

- Healthy People 2010 Objective 6-1 calls for a standardized set of questions identifying people with disabilities to be included in the core of all Healthy People 2010 surveillance instruments. Massachusetts already meets this objective; the Massachusetts disability module includes the core questions identified by the CDC for national surveillance.

Create a regional consortium of researchers in disability and public health.

- Include researchers from Harvard Medical School, Boston University, Brown University, University of Massachusetts Medical School, Syracuse University, Brandeis University, and others.
- This consortium will build on existing research relationships, stimulate inter-disciplinary collaboration and the exchange of ideas, and may be able to identify additional sources of grant funding.

Improve access to and quality of health care for people with disabilities.

OHD's activities on behalf of this goal promote the fulfillment of Healthy People 2010 Objective 6-10, "Increase the proportion of health and wellness and treatment programs and facilities that provide full access for people with disabilities".

Health care professional education

- Develop sub-committee of OHD Advisory Committee to support planning of provider education. This sub-committee should include health care providers who serve large numbers of people with disabilities, primary care providers

who serve the general population, and people with disabilities with extensive experience with the medical system.
- Identify models of care that work well for people with disabilities.
- Use *Health Access Curriculum* developed by North Carolina Office on Disability and Health and OHD to educate providers.
- Use providers with experience working with people with disabilities to conduct trainings.
- Replicate the use of persons with disabilities in standardized patient training curricula at medical schools statewide.

Create and disseminate condition-specific guidelines

- Disseminate Massachusetts Asthma Action Plan (guidelines for children).
- Create and disseminate adult asthma action plan.
- Create and disseminate guidelines for treatment of people with multiple sclerosis.
- Collaborate with a managed care organization to develop and pilot care protocols for people with arthritis that emphasize education and exercise.

Transition project

- Conduct interviews with providers to identify key issues in providing care to young adults.
- Develop model to assist providers and families in making a successful transition.
- Pilot model with targeted group of providers.

Build and expand a health and disability constituency that fosters individual and organizational awareness and collaboration to promote health and well being.

Engage people with disabilities, public health professionals, health care providers, voluntary health agencies, state agencies, and other stakeholders in a task-oriented OHD Advisory Committee.

Conduct conferences and forums on health and disability to foster inter-group dialogue, raise awareness, promote constructive collaboration, and identify future directions for OHD. The wide audience for these events will include the stakeholders mentioned above.

Expand collaboration with organizations such as the Disability Law Center to continue work of disability summit.

Continue to develop collaborations with other Massachusetts state agencies concerned with disability to promote health for people with disabilities.

OHD currently collaborates with the Executive Office of Health and Human Services, the Division of Medical Assistance, the Massachusetts Rehabilitation Commission, the Department for Mental Retardation, the Department for Mental Health, the Massachusetts Commission for the Blind, the Massachusetts Commission for the Deaf and Hard of Hearing, and the Executive Office of Elder Affairs on projects designed to integrate long-term care services, reduce the number of people with disabilities in congregate care facilities, and remove access to quality health care as a barrier to employment for people with disabilities.

These projects promote Massachusetts' fulfillment of the following Healthy People 2010 objectives:

Objective 6-7. Reduce the number of people with disabilities in congregate care facilities, consistent with permanency planning principles.

Objective 6-8. Eliminate disparities in employment rates between working-aged adults with and without disabilities.

Objective 6-12. Reduce the proportion of people with disabilities reporting environmental barriers to participation in home, school, work, or community activities.

Mentoring and replication

Create and disseminate publications describing the processes by which the Massachusetts Department of Public Health has raised the status of persons with disabilities on the public health agenda, and implemented the specific programs described above.

Provide technical assistance to other state health departments that indicate interest and potential capacity to pursue these goals.

By pursuing these goals, OHD is helping to fulfill Healthy People 2010 Objective 6-13:

Increase the number of tribes, states, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers.

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[1] A Profile of Massachusetts Adults with Disabilities, 1998-2000: Results from the Behavioral Risk Factor Surveillance System. Division of Special Health Needs, Bureau of Family and Community Health, Massachusetts Department of Public Health. November 2001